Chapter 7. Who is dying from HIV/AIDS, and how has this changed over time?

Section 1. AIDS Deaths from 1990 – 2001

Over time there has been an increase, decline and then a leveling-off in the incidence of deaths among people reported with AIDS. After reaching a peak of 1,206 in 1994, AIDS deaths declined each year until 1998, when there were 313 deaths. From 1998-2001, the number of AIDS deaths has remained steady at about 300 deaths in each of these years. Caution should be used when interpreting year-to-year fluctuations.

Trends in mortality from HIV/AIDS reflect the changes over time in new HIV infections and AIDS diagnoses. Since 1990, females have accounted for an increasing proportion of deaths. Across race/ethnicity, there has been a decrease in the percentage of deaths among Whites and an increase among Blacks and Hispanics. In the case of exposure mode, there has been a sustained increase in the percentage of deaths that are among injection drug users and a decrease in the percentage among men who have sex with men. This trend in mortality mirrors the trend seen in AIDS incidence.

In 2001, 327 people reported with AIDS in Massachusetts died. Seventy-two percent of these deaths were among men, 47% were among people of color, and 55% were among people who had injected drugs. By comparison, the profile of people recently diagnosed with HIV infection (1999-2001) is comprised of 70% men, 58% people of color, 24% among injection drug users.

One should note that the death data presented in this analysis include all deaths among people reported with AIDS in Massachusetts. This includes deaths from *non-HIV related* causes such as motor vehicle crashes, drug overdoses, and suicides. Therefore, the total number of annual deaths reported here will vary slightly from the number of *HIV-related* deaths reported in *Massachusetts Deaths* by the MDPH Bureau of Health Statistics, Research and Evaluation.

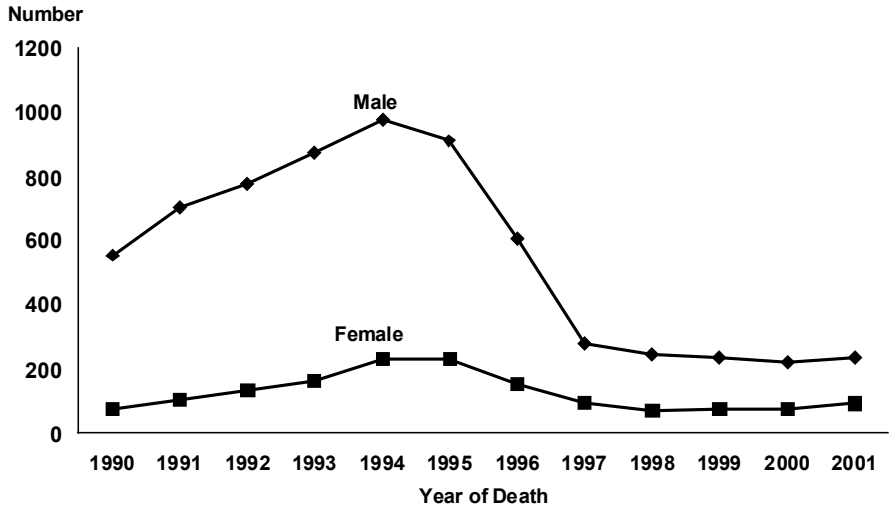
Table 7.1 Deaths among Persons Reported with AIDS by Gender and Year of Death: MA, 1990 - 2001

	Male		Female		Total
Year	N	%	%	N	
1990	555	88%	12%	76	**631**
1991	707	87%	13%	107	**814**
1992	777	85%	15%	136	**913**
1993	876	84%	16%	165	**1,041**
1994	975	81%	19%	231	**1,206**
1995	911	80%	20%	231	**1,142**
1996	606	80%	20%	154	**760**
1997	279	74%	26%	96	**375**
1998	244	78%	22%	69	**313**
1999	238	76%	24%	76	**314**
2000	222	74%	26%	78	**300**
2001	235	72%	28%	92	**327**

Data Source MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding), Data as of 7/1/02

- After reaching a peak of 1,206 in 1994, AIDS deaths declined each year until 1998, when there were 313 deaths. However, from 1998-2001, the number of AIDS deaths has remained steady at about 300 deaths in each of these years.
- Although caution should be used when interpreting year to year fluctuations, the number of AIDS deaths increased by 27 from 2000 (N=300) to 2001 (N=327), indicating the first increase in AIDS deaths since 1994.
- The number of females with AIDS who died in MA peaked in 1994 and 1995 at 231. (See Figure 7.1)
- From 1994 to 2000, deaths among females with AIDS decreased by 67%. Deaths increased, however, from 2000 to 2001 by 18%.
- Over time, females account for an increasing percentage of people who are dying with AIDS (28% in 2001 compared to 12% in 1990).
- Deaths among males with AIDS peaked at 975 in 1994 and decreased by 77% to 222 in 2000. Deaths increased, however, from 2000 to 2001 by 6%. (See Figure 7.1)

Figure 7.1 Number of Deaths among Persons Reported with AIDS by Gender and Year of Death: MA, 1990-2001



Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2002

Table 7.2 Percent of Deaths among Persons Reported with AIDS by Race/Ethnicity and Year of Death: MA, 1990 - 2001

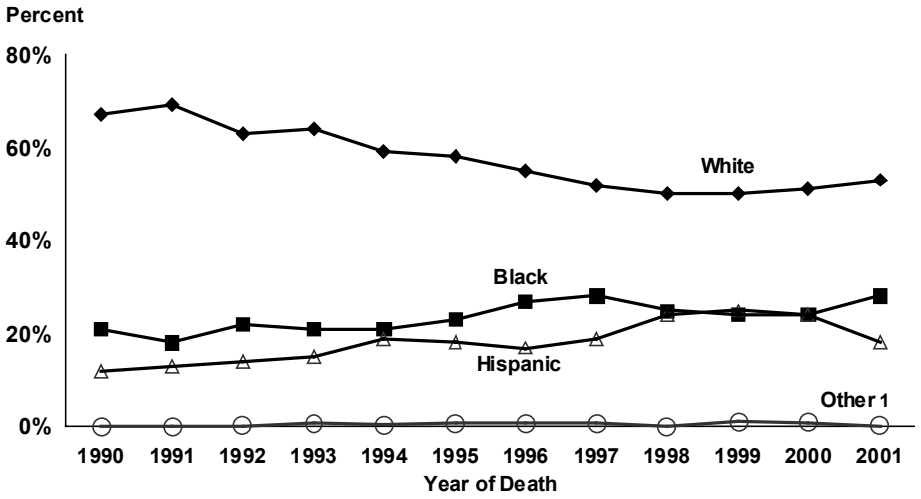
Year	White NH	Black NH	Hispanic	API	AI/AN	Total[1]
1990	67%	21%	12%	0.0%	0.0%	**631**
1991	69%	18%	13%	0.0%	0.1%	**814**
1992	63%	22%	14%	0.2%	0.1%	**913**
1993	64%	21%	15%	0.5%	0.1%	**1,041**
1994	59%	21%	19%	0.3%	0.1%	**1,206**
1995	58%	23%	18%	0.5%	0.2%	**1,142**
1996	55%	27%	17%	0.5%	0.1%	**760**
1997	52%	28%	19%	0.5%	0.3%	**375**
1998	50%	25%	24%	0.0%	0.0%	**313**
1999	50%	24%	25%	0.6%	0.6%	**314**
2000	51%	24%	24%	0.7%	0.3%	**300**
2001	53%	28%	18%	0.0%	0.3%	**327**

1 Total includes people of unknown race/ethnicity.
Data Source: MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding), Data as of 7/1/02

- Over time, people of color account for an increasing proportion of deaths among people with AIDS. (See Figure 7.2)

- From 1990 to 2001, the proportion of deaths among Whites declined from 67% to 53%, while the proportion of deaths among people of color increased from 33% (21% Blacks and 12% Hispanic) to 46% (28% Black and 18% Hispanic).

Figure 7.2 Percent of Deaths among Persons Reported with AIDS by Race/Ethnicity and Year of Death: MA, 1990-2001



1 Other includes Asian/Pacific Islander and American Indian/Alaska Native; Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2002

Table 7.3 Number and Percent of Deaths Among Persons Reported with AIDS, by Mode of Exposure[1] and Year of Death: MA, 1990-2001

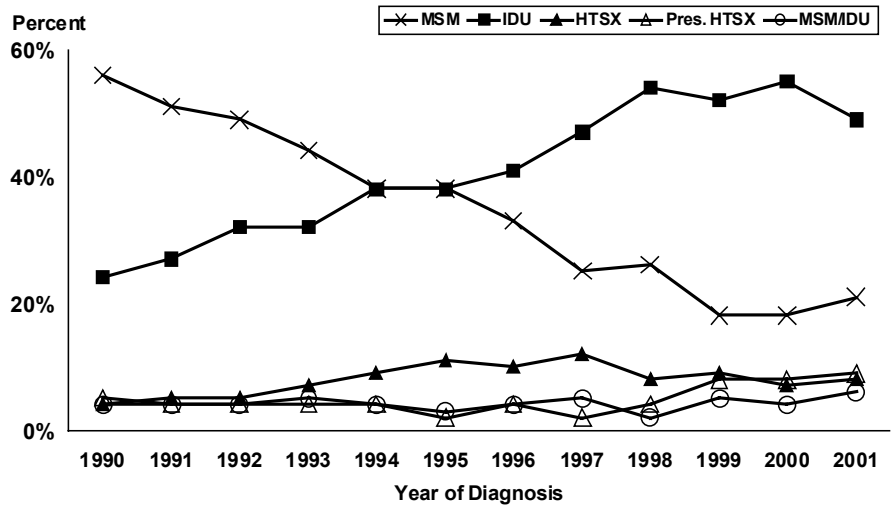
	MSM		IDU		MSM/ IDU		HTSX		Pres. HTSX		Other		NIR		To-tal
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N
1990	352	56%	154	24%	27	4%	25	4%	29	5%	27	4%	17	3%	**631**
1991	419	51%	219	27%	33	4%	43	5%	35	4%	45	6%	20	2%	**814**
1992	445	49%	293	32%	35	4%	48	5%	33	4%	33	4%	26	3%	**913**
1993	459	44%	338	32%	53	5%	75	7%	41	4%	36	3%	39	4%	**1,041**
1994	453	38%	464	38%	48	4%	105	9%	53	4%	39	3%	44	4%	**1,206**
1995	429	38%	431	38%	36	3%	130	11%	28	2%	41	4%	47	4%	**1,142**
1996	254	33%	315	41%	29	4%	79	10%	34	4%	20	3%	29	4%	**760**
1997	92	25%	175	47%	20	5%	46	12%	6	2%	14	4%	22	6%	**375**
1998	80	26%	170	54%	7	2%	25	8%	12	4%	3	1%	16	5%	**313**
1999	57	18%	164	52%	15	5%	28	9%	25	8%	13	4%	12	4%	**314**
2000	55	18%	165	55%	13	4%	20	7%	24	8%	13	4%	10	3%	**300**
2001	69	21%	159	49%	18	6%	26	8%	28	9%	6	2%	21	6%	**327**

1 See the Glossary for an explanation of Exposure Mode categories. MSM = male-to-male sex; IDU = injection drug use; MSM/IDU = male-to-male sex and injection drug use; HTSX = heterosexual sex; Pres. HTSX = presumed heterosexual; NIR = No Identified Risk.
Data Source: MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding), Data as of 7/1/02

- From 1990 to 1993, men whose reported mode of exposure was male-to-male sex accounted for the largest number of deaths among people reported with AIDS.
- In 1994, the number of deaths among persons with AIDS where injection drug use was the reported mode of exposure (464) surpassed the number of deaths where male-to-male sex was the reported mode of exposure (453).
- From 1990 to 2001, men whose HIV risk was male-to-male sex (MSM) accounted for a decreasing proportion of deaths among people reported with AIDS (56% of deaths in 1990 and 21% of deaths in 2001). (See Figure 7.3)
- By comparison, from 1990 to 2001, people with injection drug use as a reported mode of exposure accounted for an increasing proportion of deaths among people reported with AIDS (24% of deaths in 1990 and 49% of deaths in 2001). (See Figure 7.3)

Note: the category of presumed heterosexual is created to re-assign people who are reported with no identified risk but who are known to have denied all other risks except the possibility of heterosexual sex with a partner of unknown HIV status or risk. As such, it is still not clear what the exposure risk is for people in this category and any comparisons should be interpreted with caution.

Figure 7.3 Percent of Deaths among Persons Reported with AIDS by Mode of Exposure and Year of Death: MA, 1990-2001



Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2002

Section 2. Trends in Survival After an AIDS Diagnosis

The following analyses describe changes over time in the survival of people who are diagnosed with AIDS in Massachusetts.

Tables 7.4 - 7.6 provide the data from which Figures 7.4 and 7.5 are plotted. Together, these tables describe how many people died within 1 year of an AIDS diagnosis, between 1 and 2 years, between 2 and 3 years, etc., and up to 10 or more years for all people diagnosed with AIDS from 1987 to 2001. For example, the first column of Table 7.4 indicates that of 655 people diagnosed with AIDS in 1987, 276, or 42%, died within 1 year of their diagnosis; 153, or 24%, died between 1 and 2 years of their diagnosis; and 91, or 14%, died between 2 and 3 years of their diagnosis.

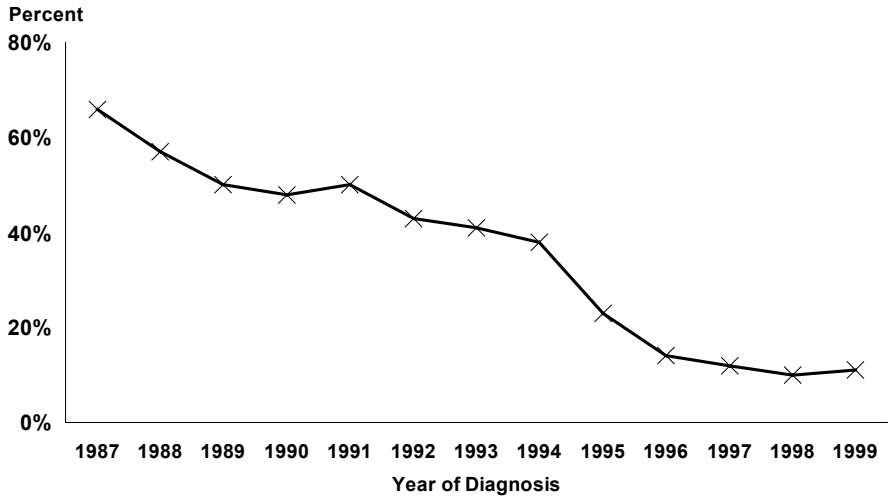
When reviewing this analysis, it should be noted that there are not as many years of data to characterize the survival of people diagnosed in later years as there are for those who were diagnosed in earlier years. For example, if a person was diagnosed with AIDS in 1987, by 1997 it could be determined whether or not the person was still alive 10 years after his or her diagnosis. However, if a person was diagnosed with AIDS in 2000, only one year of survival can be assessed, since it is still currently 2002; in 2010, it will be possible to determine how many people diagnosed with AIDS in 2000 survived for 10 years. These differences are relevant when interpreting the following tables and especially when comparing the distribution of survival times across years. With these caveats in mind, a preliminary pattern emerges in the survival analysis over time. There has been a fairly consistent decline in the percentage of people who die within two years of an AIDS diagnosis. This most likely reflects earlier diagnosis and improved care and treatment of people living with AIDS in the Commonwealth. This trend is highlighted graphically in Figure 7.4 which plots the proportion of people who died within a fixed time period (2 years) for each year of diagnosis

Similarly, Figure 7.5 shows the percentage of people who are still alive from one to ten years after their AIDS diagnosis (for people who were diagnosed with AIDS between 1987 and 1999). For example, in the trend line for people diagnosed with AIDS in 1987, 58% of these people were still alive 1 year after being diagnosed, 35% were still alive 2 years later, 21% were still alive 3 years later, and the proportion of people still alive declines with each additional year.

In comparing the trend line for people diagnosed in 1987 with people diagnosed in more recent years, it is evident that the proportion of people who are still alive is greater for each time period. This means that it appears that more people are surviving for longer time periods after being diagnosed with AIDS. Two possible explanations for these increases in survival are that people truly are living longer or it is a reporting artifact. Regarding the latter, the AIDS case definition was expanded in 1993 to include people with a CD4 count below 200. This change in the case definition would mean that as of 1993, more people are counted as having an AIDS diagnosis even though they may not have been as sick as those diagnosed with AIDS in earlier years, biasing the curves in

later years toward longer survival. At the same time, significant advances in treatment over the years likely accounts for a large portion of actual survival. The increases in survival seen in the late 80s and early 90s could be due to introduction of PCP prophylaxis, reductions in AZT toxicity, and movement towards earlier diagnosis and initiation of treatment. Increases in survival in the mid 90's may be explained by early combination therapies and the introduction of highly active antiretroviral therapy (HAART).

Figure 7.4 Percent of People Who Died Within 2 years of an AIDS Diagnosis by Year of AIDS Diagnosis: MA, 1987-1999



Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 8/1/2002

- Over time, the proportion of people who die within 2 years of being diagnosed with AIDS has decreased. (See Figure 7.4)
- Of 655 people diagnosed with AIDS in 1987, 42% died within a year of their diagnosis and 24% died within 1-2 years of their diagnosis for a total of 66% who died within 2 years of their diagnosis. (Table 7.4)
- Of 893 people diagnosed with AIDS in 1999, 8% died within a year of their diagnosis and 3% died within 1-2 years of their diagnosis for a total of 11% who died within 2 years of their diagnosis. (Table 7.6)

Table 7.4 Time From AIDS Diagnosis to Death by Year of AIDS Diagnosis: MA, 1987-1991

	1987		1988		1989		1990		1991	
Years between AIDS Diagnosis and Death	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
<1 yr.	276	42%	287	33%	291	29%	304	28%	381	28%
1 - <2 yr.	153	24%	207	24%	232	23%	212	20%	298	22%
2 - <3 yr.	91	14%	133	15%	164	16%	188	17%	193	14%
3 - <4 yr.	46	7%	68	8%	84	8%	112	10%	113	8%
4 - <5 yr.	15	2%	33	4%	63	6%	57	5%	62	5%
5 - <6 yr.	9	1%	23	3%	43	4%	37	3%	31	2%
6 - <7 yr.	7	1%	12	1%	14	1%	13	1%	14	1%
7 - <8 yr.	6	1%	9	1%	5	<1%	10	1%	13	1%
8 - <9 yr.	8	1%	4	<1%	5	<1%	11	1%	8	<1%
9 - <10 yr.	4	<1%	1	<1%	4	<1%	4	<1%	8	<1%
10+ yr.	5	<1%	9	1%	8	1%	5	1%	N/A[1]	
Still Alive	35	5%	76	9%	84	8%	126	12%	210	16%
Total	**655**		**862**		**997**		**1,079**		**1,331**	

1 Not applicable because individuals diagnosed in this year have not yet had the opportunity to survive this many years before death; Data Source: MDPH Surveillance Program; Data as of 8/1/02

Table 7.5 Time From AIDS Diagnosis to Death by Year of AIDS Diagnosis: MA, 1992-1996

	1992		1993		1994		1995		1996	
Years between AIDS Diagnosis and Death	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
<1 yr.	387	22%	365	21%	306	21%	217	16%	110	10%
1 - <2 yr.	373	21%	352	20%	246	17%	98	7%	45	4%
2 - <3 yr.	293	17%	235	13%	105	7 %	53	4%	47	4%
3 - <4 yr.	155	9%	102	6%	50	3%	45	3%	41	4%
4 - <5 yr.	52	3%	45	3%	33	2%	39	3%	33	3%
5 - <6 yr.	32	2%	34	2%	37	3%	27	2%	N/A[1]	3%
6 - <7 yr.	31	2%	28	2%	26	2%	N/A[1]		N/A[1]	
7 - <8 yr.	14	1%	28	2%	N/A[1]		N/A[1]		N/A[1]	
8 - <9 yr.	31	2%	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
9 - <10 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]		N/A[1]	
10+ yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]		N/A[1]	
Still Alive	378	22%	564	32%	674	46%	914	66%	875	76%
Total	**1,746**		**1,753**		**1,477**		**1,393**		**1,151**	

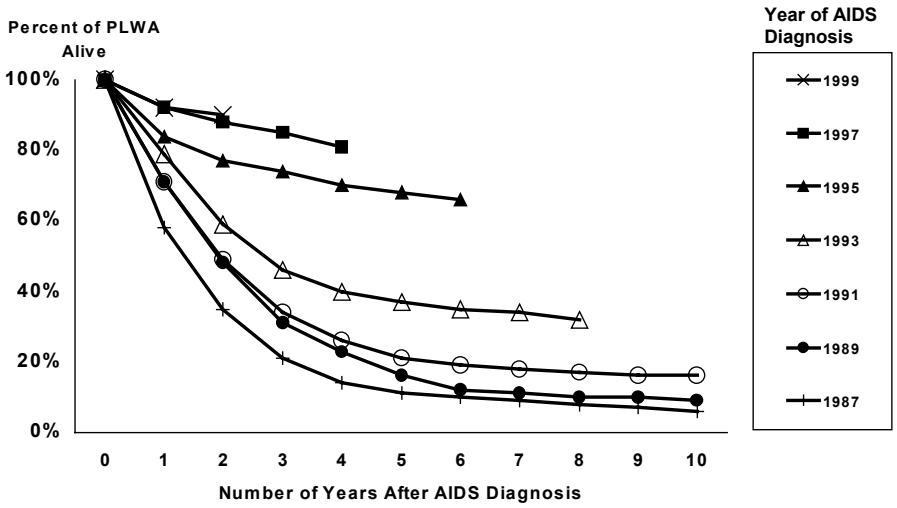
1 Not applicable because individuals diagnosed in this year have not yet had the opportunity to survive this many years before death; Data Source: MDPH Surveillance Program; Data as of 8/1/02

Table 7.6 Time From AIDS Diagnosis to Death by Year of AIDS Diagnosis: MA, 1997-2000

	1997		1998		1999		2000	
Years between AIDS Diagnosis and Death	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
<1 yr.	70	8%	56	6%	68	8%	58	8%
1 - <2 yr.	37	4%	35	4%	24	3%	N/A[1]	
2 - <3 yr.	30	3%	21	2%	N/A[1]		N/A[1]	
3 - <4 yr.	35	4%	N/A[1]		N/A[1]		N/A[1]	
4 - <5 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
5 - <6 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
6 - <7 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
7 - <8 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
8 - <9 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
9 - <10 yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
10+ yr.	N/A[1]		N/A[1]		N/A[1]		N/A[1]	
Still Alive	727	81%	819	88%	801	90%	647	92%
Total	**899**		**931**		**893**		**705**	

1 Not applicable because individuals diagnosed in this year have not yet had the opportunity to survive this many years before death; Data Source: MDPH Surveillance Program; Data as of 8/1/02

Figure 7.5 Percent of People Living with AIDS Who Are Alive 1-10 Years After an AIDS Diagnosis by Year of AIDS Diagnosis: MA, 1988-2000



NOTE: Trend lines are incomplete for more recent years of diagnosis because fewer years of observation are available; Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2002